

The Delivery of Pediatric Diabetes Care: Who is in Control? A Pilot Survey of a University Practice

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Background The morbidity and mortality associated with diabetes can be significantly reduced by timely and effective treatment. However, unless patients with diabetes have access to this treatment, and resources to utilize it, outcomes will not meet goals. We wanted to explore the impediments to effective care for the pediatric diabetes population. However, most studies evaluating diabetes care delivery have focused on the adult diabetes population, who tend to have different problems and a different constellation of providers. Evaluating the delivery of care for pediatric diabetes remains a challenging topic due to many medical, social, and economic factors. **Methods** We began by surveying 100 families with diabetic children in our university practice, seeking their opinions about the delivery of diabetes care. In a confidential questionnaire, we asked about family demographics, family experiences relating to accessibility of care, freedom to choose facility, funding, and unmet healthcare needs. **Results** Based on our pilot survey, it seems that families still have control in choosing a pediatric endocrinologist for diabetes care of their children. A reasonably high rate of second opinion visits suggests that families still have this choice. There is also evidence that physical distance to the practice is not a deterring factor from making clinic visits. Dissatisfaction with insurance companies' understanding the funding that is needed for diabetes care of children has been also noted. The survey found a desire for psychological support of children with diabetes. **Discussion** Based on this survey we can design a larger enquiry and suggest revisions in care design. It is very important to recognize and address psychological needs for family and children with diabetes. Finally, the multidisciplinary approval seems to be the key of success in providing diabetes care.

Keywords: pediatric diabetes • diabetic care • care delivery

Background

According to the Centers for Disease Control and Prevention (CDC), it is estimated that about 215,000 people younger than 20 years had diabetes (type 1 or type 2) in the United States in 2010 (CDC, 2011).*

Type 1 diabetes is immune mediated lack of insulin secretion while type 2 diabetes is a result of obesity and insulin resistance. Both types are rising nationwide. Obesity related type 2 diabetes in the pediatric population is often viewed as an epidemic (Nathan, 2010).

The CDC statistics have shown that during 2002–2005, 15,600 youth were newly diagnosed with type 1 diabetes annually and

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3,600 youth were newly diagnosed with type 2 annually. The rate of new diabetes cases was 19.7 per 100,000 each year for type 1 diabetes and 0.4 per 100,000 each year for type 2 diabetes among children below the age of ten years. Among youth between the ages of 10 to 20 years the rate of diabetes was 18.6 per 100,000 each year for type 1 diabetes and 8.5 per 100,000 each year for type 2 diabetes (CDC, 2011).

Delivery of care to diabetic children is quite different from adult care. The diabetes education at onset in children must be adapted to their level of cognitive development; must involve the family; and always involves invasive injections and monitoring techniques. For these reasons, children are more often cared for by pediatric endocrinologists than are adults, who are often taught diet and oral medication by their family physician. Funding for equipment, education, family support, and specialized care is quite different from adults.

This increased rise of type 1 diabetes and obesity related type 2 diabetes does not parallel an increased availability of pediatric endocrinologists to provide diabetes care. Lee *et al.*, found that

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the ratio of children with diabetes to pediatric endocrinologists is 290:1 and the ratio of obese children to pediatric endocrinologists is 17,741:1 (Lee *et al.*, 2008).

The specific needs of the child and family confronting newly diagnosed diabetes force dependency on a small pool of qualified caregivers, educators, and support services. As the number of diagnosed children rises, the increased load on these resources may adversely impact diabetes care for children. This makes the care planning and evaluation of outcomes in pediatric diabetes more difficult than that for adults.

Given these differences, some special problems may be as follows.

1 *Access to child-specific care.*

Families with a diabetic child ideally require an integrated support team including a pediatric endocrinologist, diabetes educator familiar with children, dietitian, social worker, and psychologist. The limited number of such teams can cause scarce appointments, high cost, long wait times, and poor coordination.

2 *Funding of care.*

Health insurance companies, facing high cost of ideal care, may divert children to the more familiar pathways of adult care, and may refuse to fund equipment, education, and support services specific to children. It may be difficult to obtain insurance or to retain coverage after the diagnosis.

3 *Choice of care.*

These problems with availability and funding may limit choices for some families who would like greater input into their child's care.

4 *Family dynamics.*

Since the child patient is not autonomous, the child's welfare depends on how well the family is able to cope with these problems, and that coping in turn depends on the family's financial, educational, and psychological resources before diagnosis. Ideally, a family with marginal resources could be identified during the education process and given special support.

There are—clearly—problems with delivery of care to children with diabetes in a system geared to adults, and many innovations are being tried to expand the reach of child-centered programs including outreach clinics, provider education, web-based education, and counseling. It is important to be able to evaluate outcomes of such care delivery innovations. Most outcome studies involve adults, and for several reasons, the outcome criteria useful in adult diabetes are less useful in evaluating care of children.

The paramount importance of intensive blood glucose control in type 1 and type 2 diabetes has significantly changed the standards of diabetes care since the results of the Diabetes Control and Complications Trial (DCCT) Research Group and the UK Prospective Diabetes Study (UKPDS) were published (DCCT, 1993; UKPDS, 1998). This has evidently changed the evaluation of diabetes care by creating clear outcome goals, at least for adult diabetes.

There are many aspects of evaluating the delivery of care in diabetes in the adult population. Evidence based approach strategies can be used to improve diabetes delivery to advance treatment plans (UKPDS, 1998). Other markers of health care facilities utilization, such as admissions to hospital or visits to emergency departments for ambulatory care with conditions

specific to diabetes, have been used as a principal outcome to evaluate the involvement of primary care networks in diabetes care within a health care system (Peterson & Vinicor, 1998).

Other parameters can be used in evaluating diabetes care including geographical, demographic and socioeconomic factors. Disparities in diabetes care and outcome have been studied by evaluating foot sores, diabetic retinopathy, blood pressure, HbA_{1c} and cholesterol and LDL levels as outcome variables (Heisler *et al.*, 2003; Hale *et al.*, 2010; Manns *et al.*, 2011).

Another area that can be evaluated in the delivery of care is the process of diabetes education itself. Diabetes education is a cornerstone in the management of diabetes. This initially takes place at the onset of diagnosis with continuous support during the progression of the disease. This can be achieved in many modalities depending on the healthcare delivery system.

Initial method of care may be an important aspect of influencing positive attitude towards diabetes with a higher sense of empowerment (Marley *et al.*, 2012).

It is clear that when the diabetic care delivery is done well, fortified with structured education, the results can be seen not only in improvement of glycemic control but also in the quality of life (Raballo *et al.*, 2012; Cooke *et al.*, 2013).

Finally, the outcome measurement of diabetic care delivery can be used as a marker for a pay-for-performance program for the health care provider (Chien *et al.*, 2012). This aspect by itself may have a great application in our evolving health care delivery system in the United States of America.

When it comes to pediatric diabetes, the evaluation of chronic complications may not yield any idea about the quality of care and the delivery of such care since these complications may not be seen during childhood. By contrast, acute complications manifested by hypoglycemia, diabetes ketoacidosis, and death, remain a major risk for the pediatric diabetes population.

A recent review by the CDC has found that type 1 diabetes death rates among youth aged 19 years or younger has decreased 61% from 1968 to 2009 (Saydah *et al.*, 2012). This clearly shows the improvement of delivery of diabetes care over four decades by measuring decreased mortality as an outcome.

A study from Oxford Children's Hospital, by Edge *et al.*, evaluated the delivery of diabetes care in children under the age of 16 years in three regions of England by analyzing hospital admissions, adverse effects during hospital stay and feedback from patients or parents. The study recommended that education of ward staff in diabetes is carried regularly with reference to the standard of care (Edge *et al.*, 2013).

The location, hospital staff availability and preparedness to deliver pediatric diabetes care are very important factors. The Diabetes Working Group of the Spanish Society for Pediatric Endocrinology (SEEP) has recommended establishing a national healthcare network for children and adolescents with diabetes mellitus and organizing comprehensive pediatric diabetes care units in hospitals focusing on quality of care (Lopez *et al.*, 2013).

Some studies have evaluated differences in pediatric diabetes care guidelines in affecting the surveillance and quality of care in the European Union countries and called for improvement of strategies towards access, equity, and quality of care (Cinek *et al.*, 2012).

Diabetes education remains a major cornerstone in pediatric diabetes care. There are many recommendations for age-appropriate education for children with diabetes and their parents in the European Union (de Beaufort *et al.*, 2012; Martin *et al.*, 2012).

Social factors may play an important role in the delivery of this education. A Danish study found that young diabetic patients from ethnic minorities had significantly poorer metabolic control compared to Danish patients (Povlsen *et al.*, 2005). The study recommended the use of professional interpreters during diabetic education to improve its quality.

Psychological factors affecting both patients and their parents need to be part of the evaluation and delivery of diabetic education as well (Malerbi *et al.*, 2012).

In the United States, the International Society for Pediatric and Adolescents Diabetes (ISPAD) clinical practice consensus guidelines 2009 compendium remains one of the most important references for the delivery of ambulatory diabetic care (Pihoker *et al.*, 2009). The ISPAD consensus examines the structure of pediatric diabetes care, the processes of care and its outcomes as well as biological outcomes for patients (Pihoker *et al.*, 2009). It stresses the importance of a multidisciplinary diabetes care team including specialized pediatricians, diabetes nurse specialists or educators, dietitians and social workers.

While the guidelines for pediatric diabetes are historically designed for type 1 diabetes care, the increased incidence of type 2 diabetes in pediatric and adolescents creates a new challenge since screening and management of type 2 diabetes in pediatrics varies widely among pediatric endocrinologists (Wong *et al.*, 2009).

It is well known that in adults, diabetes creates a large economic burden (American Diabetes Association, 2008). There is not enough data to evaluate the cost of care and cost effective outcome in pediatric diabetes but it is clear that most of patients with pediatric diabetes will transition to adult care at some point. This means that the cost effectiveness of care in pediatric diabetes will strongly influence the cost of adult diabetes in the future. The early occurrence of type 2 diabetes in the pediatric population will increase the financial burden to society.

Methods

Our practice is located in Houston, Texas. There are two major academic centers in Houston with pediatric diabetes and endocrinology services. In the past 14 years of our personal experience in Houston, we have noticed some private practices opening independently or through adult endocrinology practices that have delivered some pediatric diabetes care. Furthermore, there are some adult endocrinology specialists that would take care of young adolescent patients with diabetes. We tried in this pilot survey to evaluate the access to our clinic by asking if patients were seen by another diabetes specialist prior to their visit to us. While insurance companies always dictated the channel of referrals, we have also witnessed that many families sought our service as a second opinion. Thus, we also examined the question if families still had the option of changing their specialist even though there were not many other facilities that provided pediatric diabetes care.

The legal guardians that brought a child with diabetes were asked to fill a survey when they checked in at our outpatient clinic for a routine visit. The survey was approved (by exemption) from the Institutional Review Board of our University as a quality improvement project.

The survey has three parts. The first part collected general information about the patient (age, race, type of diabetes, duration of diabetes); household family education and income; and access to diabetes health care information (choice of health care provider, distance, role of school support, and primary care provider).

The second part questioned the satisfaction with current insurance plan dealing with childhood diabetes in regards to understanding diabetes needs, coverage of medication, diabetic supplies, and the appropriate cost of copay and out of pocket expenses for diabetes care.

The third part collected feedback about our clinic service, staff and general access. We have also asked to be graded.

All of these questions were tailored as multiple answer questions with one answer to be chosen. In most questions, guardians were given the choice of “do not know” or “prefer not to answer” to allow flexibility and avoid written explanations.

No personal data were collected, we have asked for the survey to be filled out while patients were waiting to be seen to minimize any potential interactions between family members and the care team.

Results

We asked 100 parents/caregivers to fill out our survey. The first part of the survey was to collect general information. The age group of children with diabetes is shown in Table 1.

Table 1: Age-group of children with diabetes

Age-group	%
Less than 1 year	1
1–5 years	2
Over 5 years to 10 years	14
Over 10 years to 15 years	64
More than 15 years	19

Sixty-two percent (62%) of these patients were white Caucasians, 22% were Hispanics, 3% were Asians, 10% were African-Americans, 2% have chosen other race and 1% have refused to answer.

Eighty-three percent (83%) of the diabetics were type 1 and the other 16% were Type 2. One family did not know.

Fourteen percent (14%) of the patients had diabetes for less than a year, 57% of these had diabetes for 1–5 years, and 29% had diabetes for more than 5 years.

In regards to seeking diabetes care, 39% have seen another pediatric endocrinologist prior to seeing our group and 8% have seen an adult endocrinologist.

While 83% of the families asked, felt that they had the choice when it comes to finding and seeking care by a pediatric endocrinologist, 17% felt that this was dictated by their insurance company.

When asked if insurance was not a factor in their choice, would they choose our group to provide diabetes care, 90% have said yes, and the rest of 10% felt unsure.

The approximate physical distance in one way that the family drove to reach our pediatric endocrinology clinic is shown in Table 2.

Table 2: The estimated physical distance in miles (one way) that families drove to our clinic

Physical distance in miles (one way)	%
Less than 10	3
10–25	23
26–50	47
More than 50	27

Twenty percent (20%) of the caregivers felt that physical distance between their homes and our clinic was a major factor in keeping follow up appointments. Seventy-six percent (76%) felt that it was not, and 4% were not sure about that factor.

In regards to the role of the primary care provider (pediatrician, family practice or any other physician) in the diabetes management of the child, 39% felt that the primary care providers were involved, while 61% felt that they were not.

In evaluating school support for diabetes care, 42% of the family felt that the school is involved, 50% felt that it was not, and 8% did not know.

Tables 3 and 4 list the total of household income and the highest educational level in household for either the father or the mother.

The second part of the survey targeted satisfaction with insurance companies. When asked about their feelings about the understanding of the insurance company regarding the needs of their children with diabetes, 52% had a negative response, 40% had a positive answer and 8% were not sure.

Table 5 shows the generic insurance type identified. When matched with type of insurance, 60 % of families with Medicaid and 73% with all other insurance types were unsatisfied with their insurance provider’s understanding of their diabetes needs.

Table 3: Household income

Household Income	%
<\$25,000	21%
\$25,000–\$50,000	18%
\$51,000–\$75,000	5%
\$75,000–\$100,000	30%
>\$100,000	19%
Prefer not to say	7%

Table 4: Highest education level in the household (father or mother)

Highest education level in the household (father or mother)	%
None	2%
High School	34%
Graduate Degree	46%
Post-graduate degree	13%
Prefer not to answer	5%

Table 5: Generic type of health insurance

Insurance	%
Medicaid	25%
HMO	11%
PPO	48%
Other	16%

Table 6 shows estimates for yearly copays and out-of-pocket costs (excluding insurance copay) for medications, diabetes supplies, clinic visits, and hospital visits.

Table 6: Estimates of yearly copays and out-of-pocket costs

\$ per year	Yearly copay	Yearly out-of-pocket expenses
Nothing	17	16
1–500	17	18
50–1,500	41	35
>1,500	25	31

When asked if insurance premiums have increased by the insurance company since the child has been diagnosed with diabetes 48% of the participants replied that it did, 44% replied that it did not, while 8% did not know.

We also tried to see if diabetes has caused the child to have a preexisting condition when dealing with insurance companies. 44 % of the families agreed, 41% denied, 15% did not know.

When asked about the role of insurance companies in providing enough diabetes medications, insulin, test strips and diabetes supplies, there was almost an equal number of satisfaction and dissatisfaction. Table 7 explains these results.

Table 7: Opinion about the insurance companies providing enough insulin, other diabetes medication, test strips and other diabetic supplies

The role of insurance companies in providing	Yes	No	Don't know
Enough insulin and/or diabetes medication	52	42	6
Enough test strips to test blood sugar	47	48	5
Enough other diabetes supplies	48	44	8

Finally, when asked if participants felt that the insurance plans understood their needs for child diabetes, 52 % of participants felt that they did not, 40% felt that they did, and 8% did not know. Overall satisfaction with insurance companies in relation to families with diabetic children was negative in 48%, positive in 40%, and neutral in 12%.

The third and last part of the survey was to explore the parents’ opinion about our clinic and was used as a quality improvement guideline by our team.

Overall, 97% of the parents were happy about the diabetes care that their children received in our clinic, and 3% said that they could not evaluate that (one reason was written as being new to our clinic). When asked about the most important factor that kept them with our group, 21% has identified the physician, 43% identified diabetes educators, 7% identified insurance companies, and 29% has chosen more than one factor. When asked if it was not the choice of the insurance company, would they still stay with us, 89% were in favor, 6% were not, and 5% did not know.

Table 8 shows opinion about access to diabetes care including ease to reach physicians, diabetes educators and making and changing clinic appointments.

Table 8: Easy access to diabetic care

	Yes	No	I don't know
Easy access to diabetes care	90	7	3
Is it easy to reach physician?	94	2	4
Is it easy to reach diabetes educators?	91	1	8
Is it easy to make and change appointments?	87	7	6

Since our diabetes clinic does not offer psychology service during their visit but rather on referral basis, we asked parents if they feel that children with diabetes may need psychological support. Sixty-one percent (61%) felt that the children were in need of such support, 30% felt that they did not, and 9% were neutral.

As a final step, we have asked our clinic service to be graded. Seventy-eight percent (78%) of the graders were honor pass, 20% were pass, 2% were not sure (one reason was written as being new to our clinic).

Discussion

Based on our pilot survey, it seems that families still feel that they have control in choosing their pediatric endocrinologist for diabetes care of their children. A reasonably high second opinion visit rate confirms that families still have the choice. This is a very interesting finding in a field of pediatric subspecialty in which there are not many available providers. When it comes to insurance companies policies, there are many variants that may affect and control the choice of care, but at any rate it seems that the feeling of being able to choose the physician group is still of paramount importance.

The freedom of choice of the health care provider is a major factor for being satisfied with the delivery of medical care. This is what makes the American health care system different that those in other countries. Furthermore, most of the patients have driven more than 26 miles (each way) to seek care in our clinic and most of them did not feel that physical distance between home and clinic was a major factor in keeping follow up appointments. These facts argue for the centralization of a strong diabetes delivery team, rather than fragmentation of the delivery by having different satellites clinics trying to catch more patients. It seems that families do not mind driving far to reach a physician or a medical team that they have chosen to see. This may also explain the high grading that our team has received overall.

The modern delivery of diabetes care should go beyond the pediatric diabetes team to involve family members, school team, and primary care providers. Half of the families in the survey felt that schools and primary care providers are not involved in pediatric diabetes care. Inviting school nurses and primary care provider team to be better involved in pediatric diabetes care should become our future goals in the field.

Evaluating the delivery of medical care cannot be done promptly without analysis of the role of the third party payer. It seems that insurance policies still have a major role in the establishment of diabetes care starting from contracting with health care systems, providing insulin, medication, and diabetes supplies and allowing prompt referrals to other ancillary health care providers to deal with diabetes complications and mental health.

On daily clinical practice, many families complained about lack of support from insurance companies in providing enough insulin, test strips and diabetes supplies for their children to be used and have on hand at school. In our survey, half of the families felt that their insurance companies do not understand the diabetes needs for the children, 48% were generally satisfied with them, and 2% were neutral.

We did not evaluate satisfaction, copays and out of pocket expenses according to the type of insurance (Medicaid, HMP, PPO) since there is significant variation within the same insurance plans. It is still clear however, that families with low family household income depended on Medicaid insurance and a lower out of pocket pay. Our aim was just to translate the clinical frustration that our families have expressed during clinical visits into a general survey. Involvement of the third party payers to improve the diabetes care should remain a major goal to improve the pediatric diabetes outcome. This can be achieved by continuous education and dialogue between families, health care providers from one side and the third party payers from the other side. This can be translated in cost reduction on long term basis even throughout the adult diabetes future care.

We used the last part of the survey for quality improvement goals. Most of our families seemed to be happy with the access and delivery of pediatric diabetes care. Access to diabetes care needs to be evaluated periodically and results need to be utilized to create an action plan for quality improvement. The most important result that we learned from the study was the importance of psychological support. Many families never communicated with our team for such a need, but when asked through our survey 61% felt that their children with diabetes needed that support. Our practice offers referrals to different psychology clinics but we do not provide professional psychology support during the diabetes care visit. Our future plan will focus on improvement of psychological care.

The weakness of our study comes from the fact that we have asked our existing families of patients to participate. These are probably the section of population that does not mind driving a long distance to seek medical care. A better study design should focus on families that leave our practice to understand their reasons for seeking different health care providers.

Conclusion

Since both type 1 and type 2 diabetes rates will continue to rise in the pediatric population (Imperatore *et al.*, 2012), there is a strong need to evaluate the delivery of diabetes care. Using the triad of input-output-outcome, we can evaluate the delivery of diabetes care. This can be summarized as follows:

I. Input

- 1 The multidisciplinary team
 - Physicians – (specialized or trained in pediatric diabetes)
 - Nurses – diabetes educators
 - Dieticians
 - Social workers
 - Psychologists
- 2 Continuous education of the team; staff retention, promotion and reimbursement
- 3 Payer/health insurance availability; coverage of diabetes medications and supplies; education; involvement in diabetes care and patient use for performance outcome reimbursement for the multidisciplinary team
- 4 Family involvement in diabetes care; understanding social stressors; evaluation of family structure and dynamics play a role in the delivery of care and self-learning
- 5 School, youth clubs, and diabetes camps, help provide

support and education

6 Cultural, linguistic, and special needs sensitivity

II. Output

- 1 The establishment of the pediatric diabetes care team
 - Location: permanent/mobile
 - Access: physical distance to patients
 - Equality: availability to minorities/underprivileged patients
 - Communication: continue access to team members for continued diabetes support
 - Choice: ability of patient and family to choose the team
- 2 The support of the third party payer, insurance company, hospitals and other health care establishments to prove necessary financial coverage for patients
- 3 Pharmacies: availability of medications, diabetes supplies and the method of delivery

III. Outcome

- 1 Biological outcomes:
 - Diabetes related death rate
 - Emergency room visits – hospital admission for diabetes related problems (diabetic ketoacidosis – hypoglycemia)
 - Monitoring and prevention of complications
 - Glycemic Index – HbA_{1c}
 - The transition of care to adult diabetes and the status of biological outcome at that level
 - The success of diabetes management at home and school
- 2 Patients personal outcomes:
 - Satisfaction with the diabetes care delivery
 - Quality of life improvement
- 3 Financial outcomes:
 - Cost-effectiveness outcome
 - Decrease of financial burden for diabetes related hospital visits and complications
 - Performance based reimbursement to the diabetes care team

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